**Between dispelling hope and leaving them in the state of ‘inbetweeness’: Moral dilemmas of research on infertility treatment seeking in Kerala.**

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Short title: **Moral dilemmas of research on infertility treatment seeking**

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I declare that I have no competing interests and this research was carried out as part of my PhD thesis. This paper has not been submitted elsewhere.

**Abstract:** Infertility is a condition that has inherent cultural significance. Its presence in married couples fuels speculations and assigns certain demeaning identities. The availability of technically advanced treatments for infertility provides ‘hope’ to couples and women in particular to resolve these assigned identities due to the diagnosis of infertility. The care seeking options are deeply gendered. Care seeking for infertility is a entropic cycle of success and failure and hence there is movement from one stage to another hoping for a resolution for the women studied.

The paper focuses on the dilemmas that confronted a medically trained public health professional collecting data from women who were unable to continue the suggested mainstream treatment. They were continuing in the treatment pathway by resorting to alternative but unlikely to succeed methods. I discuss the moral dilemma experienced between the need to explain the poor likelihood of success as opposed to leaving them with ‘hope’.

Key words: moral dilemma, hope, inbetweeness, infertility

**Introduction**

Infertility diagnosis is emotionally distressing (1) since it brings in a certain amount of uncertainty regarding the ability to start a family. Confronting this uncertainty with ‘desperateness’, couples navigate the treatment options for pregnancy. (2) In the infertility discourse one cannot overlook the role of Assisted Reproductive Technology (ART) which creates a certain ‘hope’ (2) with respect to this uncertainty that infertile couples live with. Treatment for infertility is emotionally and physically exhausting because it is filled with multiple failures at different points along the treatment curve for the couple either individually or jointly. Therefore, the likelihood of abandoning treatment is high for the couple along this pathway. Even though individual couples who do not meet with success do give up treatment, overall, the number of couples taking recourse to this technology continues to increase. The presence of the ART is welcomed by women, and they are pleased that this gives them at least a chance to achieve fertility despite the risks (3). This high praise for the technology is demonstrated in Franklin’s study (3), which labelled women who were in the middle of the treatment cycle as being full of ‘hope’, even though the women were not sure whether it works for them or not. Here she adds the rationale for labelling this position as ‘full of hope’, because the desirable outcome need not be a fruitful pregnancy but having given a try. For these women, the process of having attempted treatment was more important than the very success of the treatment. In this context, putting an end to the pursuit of having a child means the end of hope in their lives. The very ‘hope’ that enabled them to persevere with treatment for infertility overcoming the multiple stressors including failure to achieve a child, also helps them to deny the potential childlessness(4).This means that trying the different treatment methods that are available out there was of utmost importance before completely abandoning the treatments. Franklin (3) also noted that the decision to abandon ‘hope’ to achieve pregnancy is a difficult decision for the couples since at each stage they revisit the decision and gauge it on many ‘what ifs?’.This means when they decide to abandon treatment, they are still holding on to the fine thread of ‘hope’ that it may happen at least this time with this particular treatment.

Here, I examine the moral dilemma in dispelling such ‘hope’, the ‘hope’ that could hold an important part in the day to day existence of couples with infertility. It calls for weighing dispelling such ‘hope’ against the alternative of allowing couples to live with it. This dilemma is partly a consequence of who I was. I therefore have included my positionality, ie., the worldview that I hold, in the discussion of the moral dilemma.

**Moral Contexts**

Moral dilemmas are part of the everyday practice of research(5), even though they are often not delineated as moral challenges. They are challenging because they pull a researcher in two or more equally compelling moral directions (6). In field situations a researcher tends to get mired in various interactions with individuals, some of which impose multiple obligations. It is difficult to make a choice across these multiple obligations as there is no hierarchy of morality surrounding these choices(7). The choice regarding which way to act is determined usually by the context in which the dilemma happens and the world view of the researcher (8). Even after making a choice, the rejected alternatives remain unfulfilled, making moral failure an inevitable component of the resolution (9).

This article explores the moral dilemmas I faced as a researcher while interviewing women who at the time of interview were not pursuing the treatment for infertility suggested by the treating medical professional. The treatments suggested by the professional from a medical perspective was the only possible method that could offer a potential solution to their problem. The couples had either abandoned all kinds of allopathic treatments or were trying other systems of medicine or alternate forms of remedy.

**Positionality of researcher**

It is important here to state my position as that would enable readers understand the dilemmas I faced. First and foremost being a woman researching this particular problem, I was not able to detach my reproductive body from the women I was interviewing. I could feel for myself how the meaning of motherhood resonated with those women. I am also a trained nurse and a public health doctoral student studying the infertility treatment seeking pathway of couples. As a trained person in modern medicine and a researcher looking into the infertility treatment seeking pathway, I have sufficient understanding of infertility and its treatment. But I was not a specialist doctor who would have been able to suggest with definite authority that a certain treatment was better than the other for the participants in my study. I do have a strong biomedical orientation due to my training. I had approached the participants of the study through the health system and most of my participants were informed of my research topic by the health system representative, the Accredited Social Health Activist (ASHA worker). She in turn had informed them that someone will be coming to talk to them about their treatment. Hence for the participants, I also embodied ‘hope’ as someone who could offer them some sort of help to bring in resolution to their problem.

**Ethics Approval**

The study was cleared by the Institutional Ethics Committee of SCTIMST, the IEC clearance number SCT/IEC/1112/JULY-2018 dated 03.08.2018. Written informed consent was obtained from all the participants prior to the interview. The participants were first contacted through ASHA worker and permission was sought for interview. Only if the participant gave permission I visited them at their home. After explaining to them the purpose of the study and getting their permission did I started collecting the data.

**Methods**

The objective of the research study was to describe the care seeking pathway of couples with infertility. The study method was a community-based survey, where 604 women who were part of a couple seeking care for infertility (one or both of the couple were diagnosed to have a problem) were interviewed using a structured interview schedule. These women were either currently seeking care or had a history of seeking care for infertility. Women were the primary respondents in the study although the data was collected for a couple. This was because of the assumption that women may be recalling the treatment details better than men, as in most cases some form of treatment may be happen on the women’s body.

Care seeking is defined in the study to include all the methods adopted by the couples to resolve infertility. It includes biomedical treatment, alternate systems of medicine, alternate methods like religious methods, faith based and magic remedies, traditional medicine etc. Treatment would include here only modern medicine and AYUSH.

The study sample included women from three districts of Kerala, Thiruvananthapuram, Kottayam and Malappuram. The 14 districts of Kerala were ranked based on the expected level of infertility. The districts were grouped into three categories based on their expected level of infertility as low, middle and high levels of infertility. One district from each group was selected. This brought in necessary variation in the infertility treatment seeking experiences in terms of age at marriage, educational levels and religious denominations. The study documented the various treatment options used to resolve infertility across all types of centres and the reasons, if any for discontinuing treatment at specific centres. The data analysis was done using R software version 1.2.1335. A descriptive analysis of the care seeking pathway of the couples across 11 centers was done. This was done to understand the treatments suggested to the couples and the reasons for transition from one center to another.

I looked at this study from a feminist perspective. The study is rooted in the understanding that there is a social burden to infertility and that it is gendered. This means, even when the inability to reproduce is caused by male factor infertility, its burden has to be borne by women. The presence of reproductive technology which offers solutions to couples with infertility burdens women unequally when compared to the men. That these services are more frequently located in the private sector creates additional barriers to access.

**Care-seeking trajectory for infertility**

A total of 604 women were interviewed regarding their treatment seeking pathway, out of which 75.7% (457) of the women no child at the time of interview and they were either continuing treatment(35.9%), stopped treatment completely (24.1%), were taking a break from treatment (36.8%), others mentioned that the doctor asked them to wait, or that partner was unwilling or they were trying religious methods (3.2%). Table 1 below shows the status of treatment of women who were not having child at the time of interview.

Table1: The status of treatment for women who did not have a child at the time of interview, (n=604)

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Status of women**  **at the time of interview** | | Continuing treatment | Stopped treatment completely | Taking break from treatment | Partner un-willing to continue | Currently no treatment suggested | Trying religious methods |
| No child | 457  (75.7%) | 164  (35.9%) | 110  (24.1%) | 168  (36.8%) | 1  (0.2%) | 12  (2.6%) | 2  (0.4%) |
| Had child/  Pregnant | 148 (24.5%) | - | - | - | - | - | - |

Women visited any number of centres, ranging from to 1 to 11 centres, while some continued to seek treatment, some dropped out of treatment temporarily and others stopped treatment permanently. They reported multiple reasons for exiting each centre. Among these reasons some said that they abandoned treatment at one centre because they did not want to undergo the treatment suggested at that particular centre. This was often mentioned when the suggested treatment was IUI or IVF[[1]](#footnote-1). The respondents either proceeded to the next centre or stopped the treatment altogether. The specific reason for stopping ART treatments were personal including the unacceptability of use of donor sperm and financial difficulties. Couples do not exhibit the same level of reluctance with respect to donor eggs when compared to donor sperms(10). The use of donor sperm was not acceptable compared to donor eggs because maternal relatedness was not considered as importance as a father’s in a patriarchal society (11). Men and women felt that use of donor sperm will lead to marital issues. The negative attitude to use of donor sperm was also attributed to an incomplete gestational experience, societal opinions(11).

During the community based survey the researcher encountered couples in this category who abandon treatment when IUI or IVF was suggested, even though the treatment did not always include use of donor sperm. The couples choose not to attempt IUI and IVF/ICSI, as they were reluctant to undergo such treatments due to the fear of using donor sperm, even when the option of using one’s own sperm was suggested.

They were confused by the understanding that if their partner has sperm, then why do they have to undergo the ART procedure? In many cases they also mentioned religious reasons as one of the factors hindering the use of this technology. They also reported that they continue to live with the hope that pregnancy will happen in the due course due to the presence of sperm. Many abandoned the modern medicine treatment to try Ayurveda or Homeopathy or other alternate methods like religious or folk remedies to achieve pregnancy.

In the study 32(5.3%) women were suggested IUI, and 128 (21.2%) were suggested IVF. Among this collective group, 115 (19.0%) did not want to continue the treatment suggested by the doctor. Two fifths of those suggested IUI (40.6%) and more than three fifths of those suggested IFV (62.5%) did not pursue it as they did not want to take up those treatment options.

When couples shift from one centre to another, the reason for transition can be disinterest in continuing the specific treatment that was suggested like IUI or IVF. This also means they tend to move from modern medicine to other alternate systems of medicine for treatment or alternate methods for resolution of their problem. This transition is demonstrated in table 2, when couples move from centre 1 to centre 2. Table 2 shows the transition of couples from one centre to another.

Table 2:The transition of couples from centre 1 to centre 2, when IUI or IVF is suggested as the treatment

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | Another centre visited  n=604 | Suggested treatment in this centre  (Centre 1) | | Discontinued since not want to continue the suggested treatment | | Ayurveda or Homeopathy or alternate methods as next point of care by those who were suggested | |
| IUI | IVF | IUI  (n=5) | IVF  (n=11) | IUI  (n=5) | IVF  (n=11) |
| Yes | 493  (81.6) | 5  (1.0) | 11  (2.2) | 2  (40.0) | 7  (63.6) | 4  (80.0) | 4  (36.4) |
| No | 111 (18.4) | 2  (1.8) | 3  (2.7) | - | 1  (33.3) | - | - |



A possible reason for not wanting to undergo IUI or IVF is the assumption that a donor sperm will be part of the treatment or that they are told that donor sperm is part of the treatment options.

The decision to stop the treatment means that they will exit the pathway of care seeking and that there would be not additional biomedical intervention to resolve infertility for the woman. The women in this situation remain in a state of limbo, a state of ‘inbetweeness’ according to Probyn (12) without care and not entirely abandoning care seeking either. For women, to not to abandon seeking care is important as the onus of reproduction is seen to fall upon them in the social contexts they live in (13).There is no avenue left to prove her reproductive body as normal in instances where her partner is the cause for infertility. This redirects the pathway into alternate methods of care seeking. This includes consuming different ayurvedic formulations sold under the guise for improving the semen parameters, folk remedies like consuming “naikarunaparippu” (Velvet Bean- Mucuna pruriens) powder in milk, astrological remedies, eating other “divinised” things like banana, ghee to achieve pregnancy.

**The moral dilemma – to dispel hope or to leaving them with ‘hope’**

I faced dilemma while conducting the survey where I encountered repeated accounts of women reporting that they had stopped modern medicine treatment and were pursuing other systems of medicine or alternate methods to resolve infertility. The reasons cited included among the other things, that they were (read as their partners were or both were) uninterested in pursuing the particular treatment suggested by the doctor i.e., IUI or IVF specifically. They also reiterated that they were hopeful of the success of the particular remedy they were using. This has been reinforced by them by pointing out anecdotal accounts of people who had a positive outcome by that means.

In these situations, I was confused as to whether to explain to them that this is false hope and they should seek treatment or continue the treatment suggested by their biomedical doctor. I think my strong affinity towards modern medicine stemmed from the biomedical perspective that shaped by my training. I came from the biomedical school, and hence my reluctance to acknowledge the positive effects if any of the alternate system of medicine. I did not have the scholarship to understand the working of this system. I also believed that the alternate methods like religious methods or eating some traditional powders were not going to give them positive results.

But on further reflection, I was confronted with the thought that whether it would it be right to dispel the ‘hope’ that makes them lead their life as it is? In certain cases, when the couples were diagnosed with absolute male infertility, the use of donor sperm was the only available biomedical option. I was sure in such cases that the participant was never going to undergo that treatment due to personal, cultural and religious reasons. The dilemma was whether it was worth dispelling the ‘hope’ with which people lived in or provide accurate information about their situation, of course from a biomedical perspective.

The second dilemma concerned the option of informing the couples that the only method is to undergo IVF which is an expensive treatment and has less than 40%(13) chance of being successful( while the mean live birth from one cycle and its subsequent cryo-cycles was only 33%)(13).Many of those in these situations were of low socio economic status and it was not clear to me as to whether resorting to these treatments that do not provide 100% success is worth their money. Most of the respondents in the survey were of middle socio-economic status across all the three districts. Approximately 50 percent of the respondents were Hindu while 33 percent were Muslim and 17 percent were Christian. Majority of the respondents were educated more than high school level, and only 0.3 percent were only illiterate. This was again a judgement call that I was making on the basis of my own middle class values, both judging their socio-economic contexts and their biological options.

I approached the participants with an assumed position of ‘knowing’ (15), I was both knowledgeable of the particular issue under study and I was also empathetic towards the women who were going through this whole infertility conundrum. Being a woman with a reproductive body enabled me to empathise with these women at a more personal level and hence it was difficult for me to cut their one fine thread of ‘hope’ that they were holding on to. And I also assumed a position of power in the field, because I was talking to them from within the health system. So I had to be cautious of the my responses since the role I assumed and the one assigned to me by my participants would have jeopardised their ‘hope’.

Stopping the care seeking for infertility altogether means that they no longer can dwell in the hope that gave them the power to stay in the state of childlessness and pursue the exhausting treatments. It is also this ‘hope’ that has pulled them together by a narrow thread between the state of being able to achieve a pregnancy and the potential to be labelled as barren for the rest of their lives, even when the infertility is contributed by the reproductive impairment of the partner. When the norm of the binding binary that is prevalent in most categorisations, the state of belonging to the category of infertile is not something one wants. When the ability to move to the category of not infertile is hampered or is delayed, one would like to remain in the space between the two i.e., between of the categories. ‘Inbetweeness’ as mentioned by Probyn (12)is the movement that happens when the wish to belong is there. So the women may wish to be in this safe space of “inbetweeness”[[2]](#footnote-4) (12), where they find the solace of not being labelled as something stigmatising while still waiting to achieve the state of motherhood.

The discourse of infertility emphases on the social construction of infertility (16) and how such a construction shapes the decision-making process for treatment and its effect on the men and women seeking treatment. This social construction of infertility puts the onus of reproduction on women and childless women are subjected to social ridicule and stigma(17). Thus, women become the primary reproductive agents among the couple and hence the inability to reproduce challenges their ability to do so primarily. This idea that women’s bodies as the bearers of reproductive impairment within the couple in the absence of a pregnancy makes the women embody the idea that inability to reproduce is their fault (18–20).

The idea that women may be having the reproductive impairment coupled with social ridicule and facing prying questions from family and friends regarding the pregnancy status, drives them into the treatment seeking pathway. They are also worried about their future, be it their problem or their husband’s problem, the burden of care lies with the women. Women are fraught within the whole infertility conundrum, where they have to take the ‘burden’ (of infertility and its treatment) and the ‘blame’. It is their bodies that pass through the scrutiny of the family, society and the medical tests and procedures (13,21). Men are able to detach themselves from the responsibility of the blame due to the social construction of infertility and from the invasive treatments due to the biology of reproduction.

This position of women makes it imperative to prove that their bodies are functional and hence put them through the battery of invasive procedures. Here ‘hope’ that is portrayed by the technology plays a role in helping the women to prove their bodies as capable of conforming to the social norm. This also is the reason for them relentlessly going through the rigorous treatment processes, making use of multiple centres even though they are tired both physically and emotionally due to the invasiveness of the procedures and the absence of the desired results.

When they are unable to undergo a specific test they are advised due to the recalcitrance of their husbands they perforce resort to other measures to prove themselves as functional viz., the alternate methods. Abandoning care seeking here means an end to the ‘hope’ and the many comforts that it offers. Even if it is the religious or astrological remedies, the women I had interviewed talk with such unwavering belief that they will be able to get pregnant if they follow the remedies suggested. And I was seen as someone who was there to seal their ‘hope’ and not as someone who could dispel theirs. These alternative remedies emerge out of the socio-cultural milieu of the couples’ lives and the value system that they subscribe to.

Dispelling their expectations came with the burden that there was no pragmatic solution to offer from my middle class biomedical perspective. Explaining the real nature of the problem and the potential solutions meant losing the only intangible thing that they lived with in spite of not achieving their desired goal of fertility, viz. their hope. Moreover, this hope is also inter-twined with their value system that emerges from their culture. I chose the second option in this context, given the dual problem of lack of resources and the unacceptability of donor sperms for the couples. So, I walked away completing the interviews, leaving women in the state of ‘inbetweeness’. The burden of living with that choice and not dispelling the information asymmetry between researcher and researched is my own.

**Acknowledgements**

I would like to thank to my PhD guide Dr. Mala Ramanathan, Professor, AMCHSS, SCTIMST for reading the manuscript multiple times and correcting it, which helped me shape the manuscript in its present form. I would like to thank Dr. Rakhal Gaitonde, Professor, AMCHSS, SCTIMST for reading the manuscript and giving valuable comments. I would also like to thank my colleague Ms Sapna Mishra for enabling identification of repetitive portions of the earlier drafts. Errors if any are entirely mine.

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1. Here, when I refer to IUI or IVF it also includes those using donor sperms for fertilization in some cases [↑](#footnote-ref-1)
2. A term used by Elspeth Probyn to denote the “the constant way that one is always in between two languages, cultures, and histories ” [↑](#footnote-ref-4)